



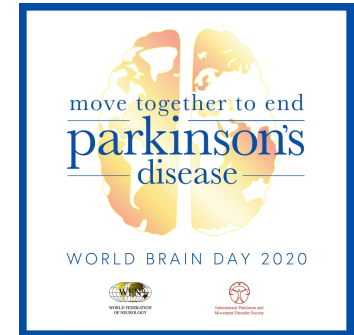
RAISE AWARENESS FOR PARKINSON'S DISEASE AND TELEREHABILITATION: A TREATMENT OFFER TO FACE UP PANDEMIC

Rehabilitation Neurology Division
Maugeri Clinical Scientific Institutes



The involvement of the psychologist in the telerehabilitation programmes





THE INVOLVEMENT OF THE PSYCHOLOGIST IN THE TELEREHABILITATION PROGRAMMES

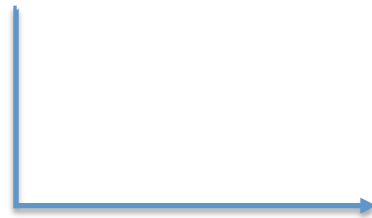
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Veruno Institute

STATE – OF – ART OF THE PSYCHOLOGIST IN TELEHEALTH

Involvement of the psychologist in telehealth - telerehabilitation of:

- Chronic pain patients *(Cranen et al., 2011)*
- Heart failure patients *(Piotrowicz et al., 2016)*
- Parkinson's disease patients *(Pretzer-Aboff et al, 2015; Swallowell et al., 2018)*



Remote psychological interventions are efficient

PARKINSON'S DISEASE (PD)

Motor symptoms

Non-motor symptoms

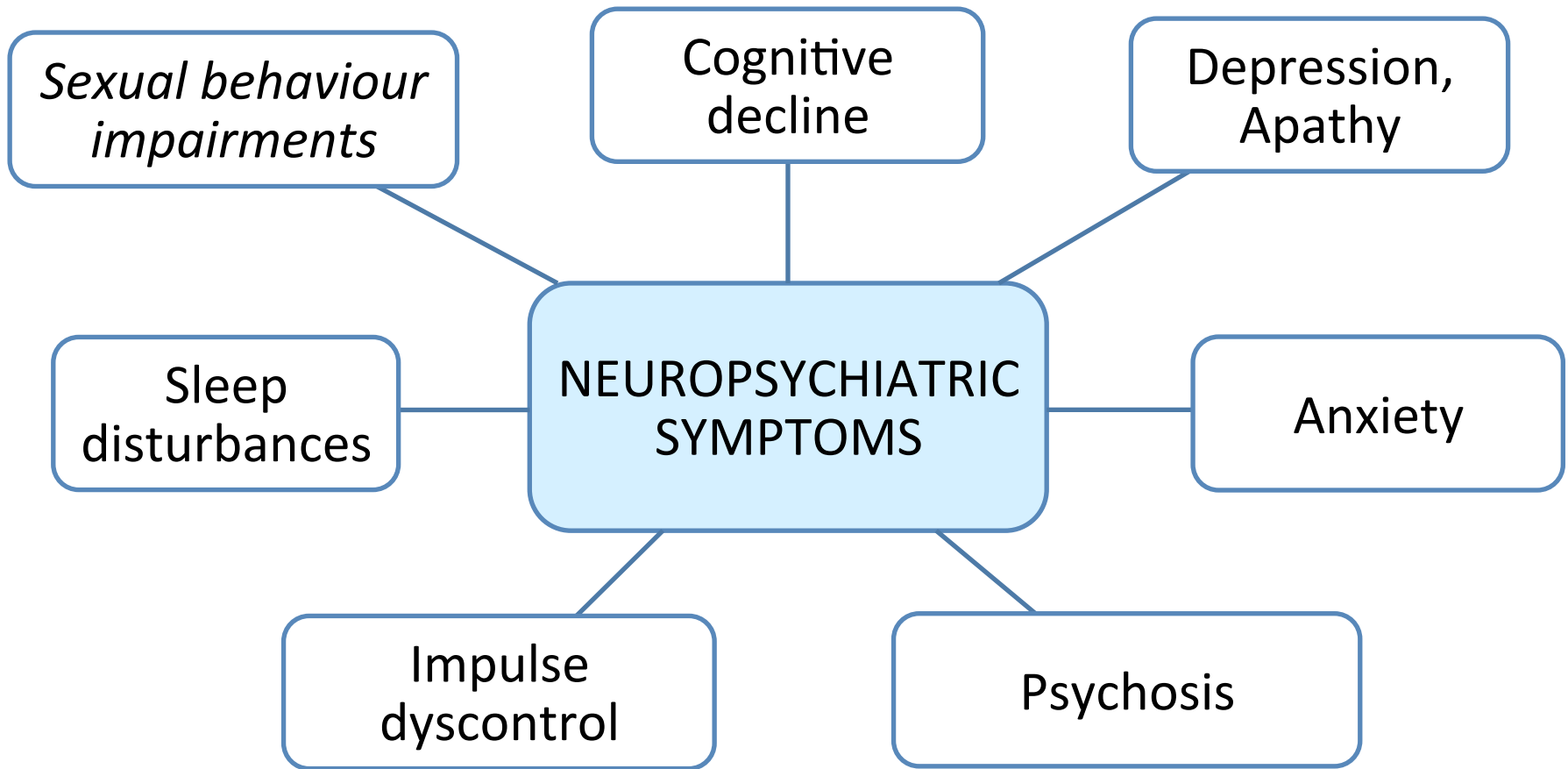


NEUROPSYCHIATRIC
SYMPTOMS

- Magnify disability
- Increase the need for supervision
- Affect emotional aspects of the relationship with a caregiver

(Mosley et al., 2017)

NON-MOTOR SYMPTOMS



(Grover et al., 2015; Pfeiffer, 2016; Mosley et al., 2017)

PD PSYCHOLOGICAL INTERVENTION

EVALUATION



INTERVENTIONS



OUTCOME



Improve **QUALITY OF LIFE**

CAREGIVER

“The unpaid person who primarily cares for the patient because of emotional ties regardless of any family relationship”

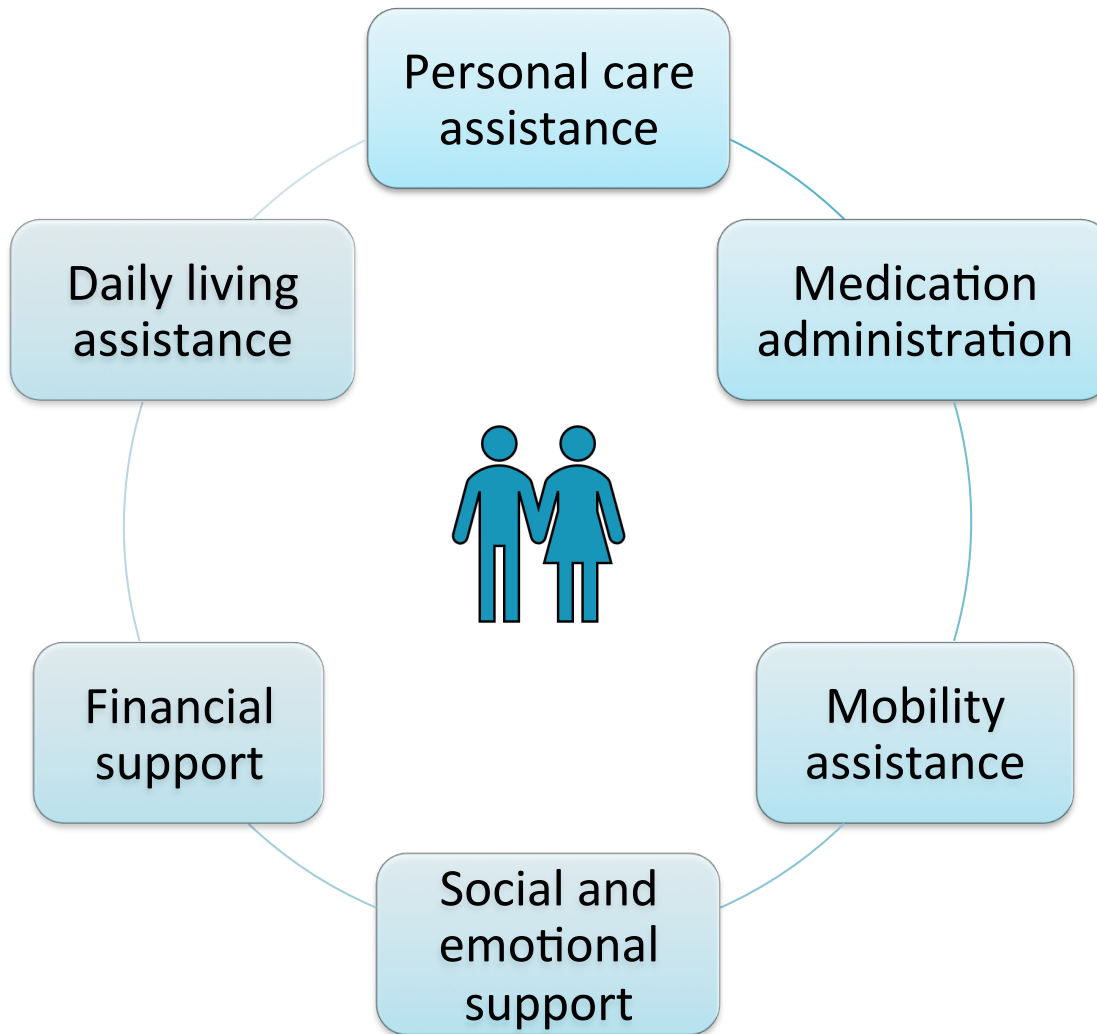



It's not possible to consider the patient without her/his caregiver

What about chronicity?

(Rossi et al., 2001; Vidotto et al., 2010)

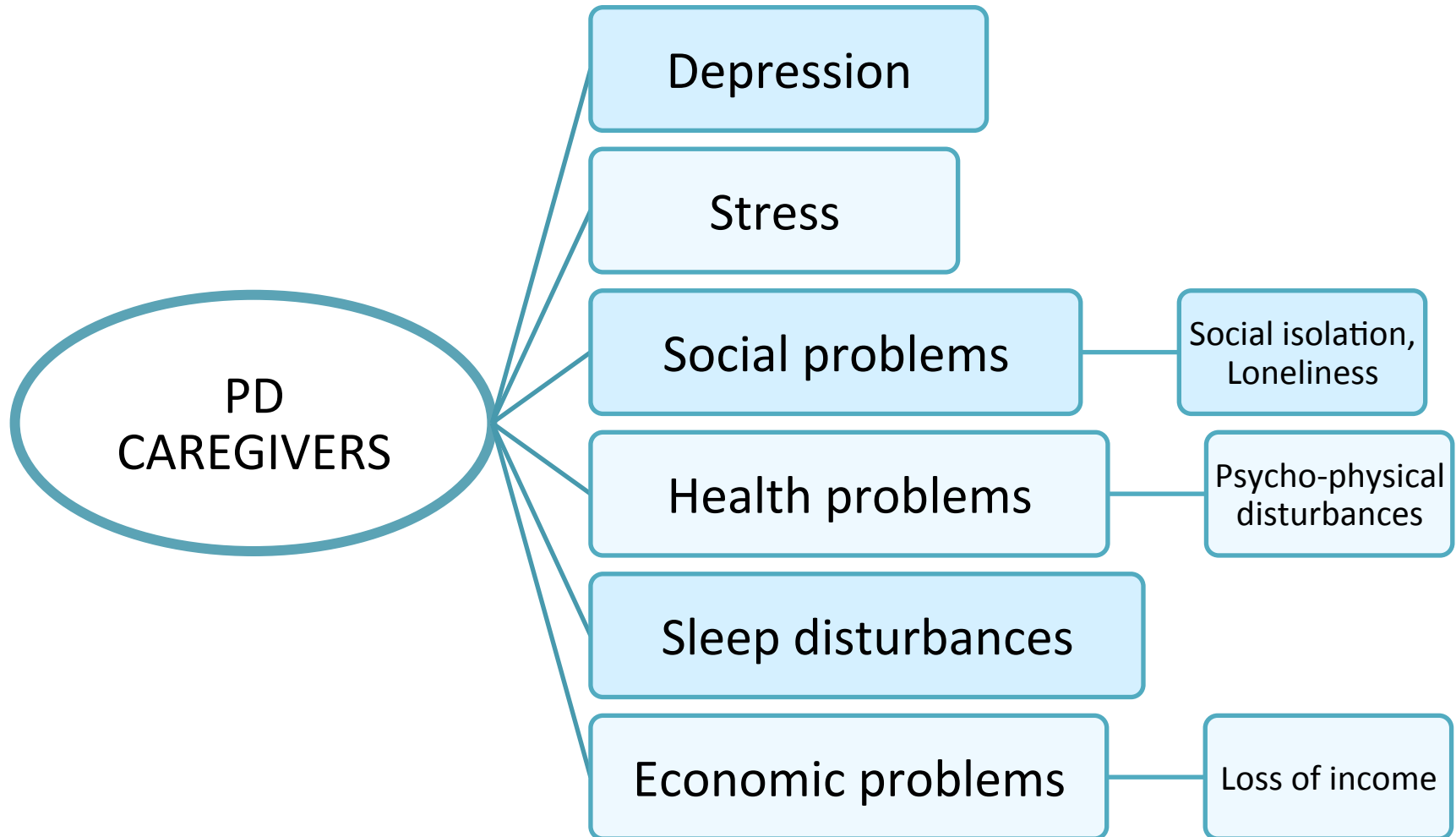
PD CAREGIVER RESPONSIBILITIES



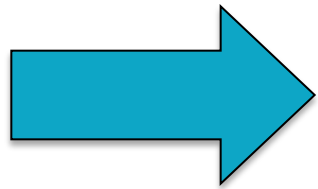
- 
- Less leisure or social activities
 - Physical and mental fatigue
 - Lower QUALITY OF LIFE

(Mosley et al., 2017; Smith et al., 2019)

PD CAREGIVER CONSEQUENCES

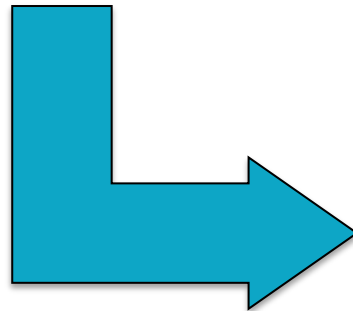


(Happe et al., 2002; Graham et al. 2006; Schrag et al., 2006; Martinez-Martin et al., 2012)



**CAREGIVER
BURDEN**

- “The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning” (Zarit & Zarit, 1986)



**Less
effectiveness
of caregiving**

- Frequent hospitalizations
 - Lower Quality of Life
- (Kuzuya et al., 2011;
Mohamed et al., 2010)*

WHY TAKE CARE OF THE CAREGIVER?

Influence on patient's acceptance of the disease

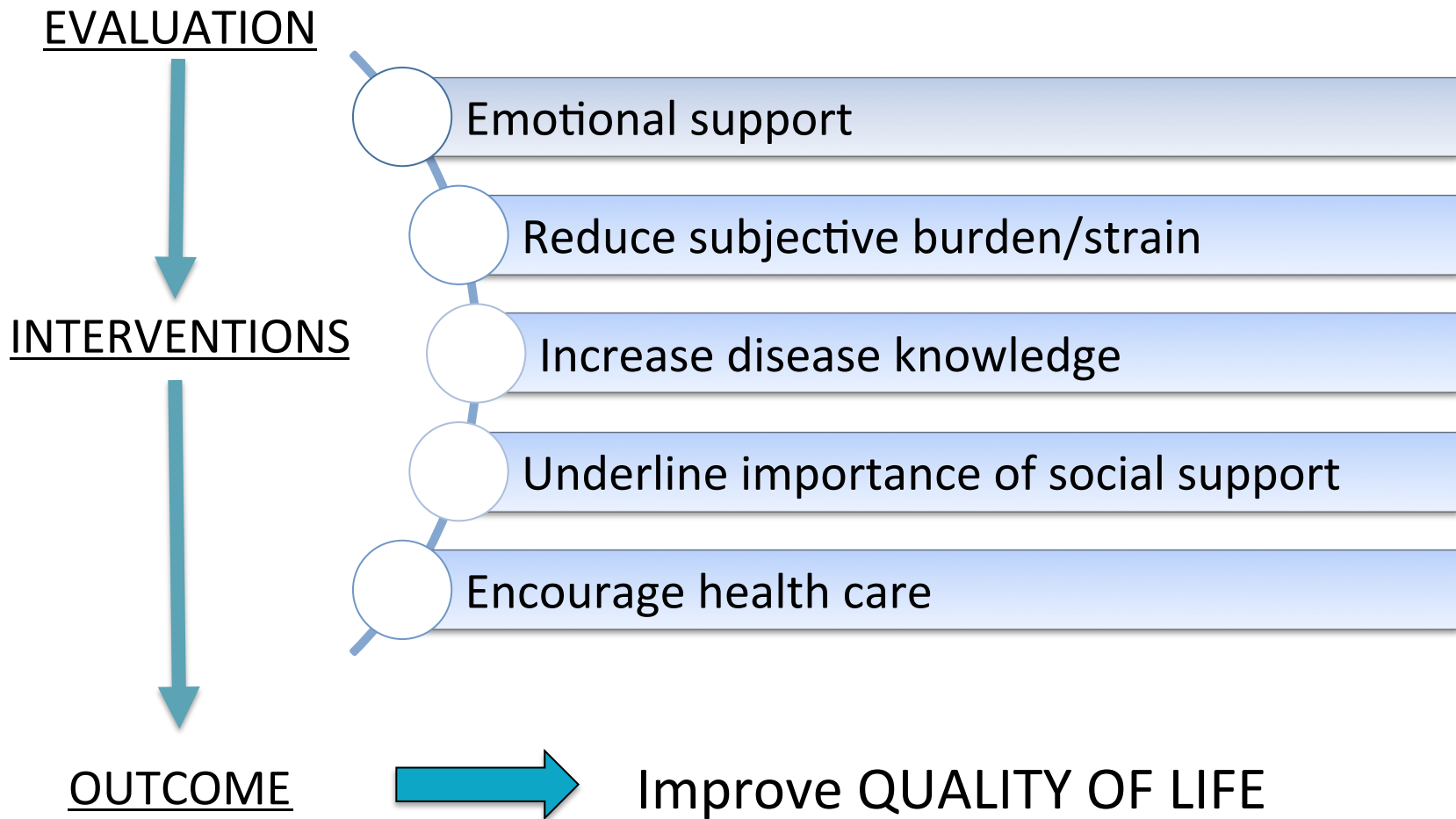
Influence on patient's compliance

Compensation for economic and structural deficiencies



Reasons directly related to the patient

THE PSYCHOLOGIST FOR PD CAREGIVER



TELESUPPORT FOR THE CAREGIVER

- ✓ Review of telehealth tools and interventions to support family caregivers: satisfaction and improvements in caregivers' outcomes *(Chi & Demigris, 2014)*
- ✓ PD caregiver telesupport group: positive feedback *(Shah et al., 2015)*
- ✓ Telehealth intervention: reduced dementia caregiving-burden *(Lindauer et al., 2019)*

TELEMEDICINE

Activities in ICS Maugeri (Veruno):

VAMP* – Disease management*

TELEPARK

REPORT

5x1000

VAMP: THE ROLE OF THE PSYCHOLOGIST

360 ° professional assistance for disease management

- Psychological and cognitive assessment interviews
- Support interviews

TELEPARK: THE ROLE OF THE PSYCHOLOGIST

- Psychological and cognitive assessment interviews
- Continuing the psychological intervention started as soon as enrolled to deal with the emotional discomfort and problems related to the acceptance/management of the disease (for patient and caregiver)

REPORT: THE ROLE OF THE PSYCHOLOGIST

- Assessing the presence of emotional disorders, the quality of life and the cognitive functioning of the patients
- Assessing caregiving-related strain in caregivers
- Supporting by telephone the caregivers of patients that follow the home rehabilitation program

5X1000 PROJECT

Assessment of caregiver's role during telerehabilitation of patient with Parkinson Disease and sleep disorders.



To study the impact on the caregiver in terms of stress, frustration, sleep disorders, anxiety or depression and illness denial-disperception.

Patients are randomized into two groups:

- Group T: caregivers of patients who will follow telerehabilitation.
- Group C: caregivers of patients who will undergo normal rehabilitation training.

Each patient and caregiver will be assessed at T0 and T1:

Patient	Caregiver
Quality of life	Burden
Emotional disorders	Emotional disorders
Illness denial	Illness denial
Sleep disturbances	Sleep disturbances
Cognitive functions	

5X1000: THE ROLE OF THE PSYCHOLOGIST

- Patient's assessment:

MOCA

- Cognitive screening

AD-R

- Anxiety and depressive symptoms

PDQ-8

- Quality of life

IDQ-R

- Illness denial

ISI

- Insomnia

ESS

- Sleepiness

- Caregiver's assessment:

AD-R

- Anxiety and depressive symptoms

FSQ-SF

- Caregiver burden/strain

IDQ-R

- Illness denial

ISI

- Insomnia

ESS

- Sleepiness

- Telesupport for the caregiver every two weeks by telephone

5X1000: SLEEP DISTURBANCES IMPACT

The motor impairment in PD is associated with sleep fragmentation, early awakening, nocturnal cramps and nightmares.



Sleep disturbances are prevalent in PD caregivers.

The poorer is the quality of sleep and the poorer is the quality of life perceived by the caregivers.

(Happe et al., 2002; Cupidi et al., 2012)

PATIENT' S COMMENT

“Essere parte di un progetto di teleriabilitazione, mi fa sentire accolto e seguito”

- ❖ More active role in self-management *(Kenealy et al., 2015)*
- ❖ Patient satisfaction *(Wilkinson et al., 2016; Kruse et al., 2017)*
- ❖ PD patients benefit greatly from multidisciplinary - interdisciplinary medical care *(Pretzer-Aboff et al., 2015; Ben-Pazi et al., 2018)*



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